

Treatment Experiences of Infertile Women with Endometriosis: A Qualitative Analysis

Shakeela Ishrat^{1*}, Farzana Deeba², Shaheen Ara Anwary³, Jesmine Banu⁴, Parveen Fatima⁵

¹Associate Professor, Department of Reproductive Endocrinology and Infertility, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh.

*Corresponding author

²Associate Professor, Department of Reproductive Endocrinology and Infertility, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh.

³Assistant Professor, Department of Reproductive Endocrinology and Infertility, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh.

⁴Professor, Department of Reproductive Endocrinology and Infertility, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh.

⁵Ex- Chairman Department of Reproductive Endocrinology and Infertility, Bangabandhu Sheikh Mujib Medical University, Chairman and Professor of Obstetrics & Gynaecology, Care Medical College Hospital, Dhaka, Bangladesh.

Received: March 2021

Accepted: April 2021

Abstract

Background: Endometriosis is a chronic, recurrent, inflammatory condition associated with the presence of functioning endometrial tissue outside uterus. Endometriosis affects around 10% of women in reproductive age. The women with endometriosis may be asymptomatic with an incidental finding of chocolate cyst or ovarian endometrioma at sonogram. Aim of the study: To explore the treatment experiences of infertile women with endometriosis.

Methods: This was a qualitative study of the infertile women who were counseled in the Endometriosis Clinic of the Infertility unit of the Department of Obstetrics and Gynecology of Bangabandhu Sheikh Mujib Medical University over a period of 5 years from 2014 to 2018. The women were contacted over cell phone in the month of July 2020. Short semi- structured interviews were taken with both open and close ended questions. Data collected from the records of Endometriosis Clinic and from the semi-structured interview were used for qualitative analysis. **Results:** Only 50 women could be reached for telephone interview among of the 160 women with endometriosis who attended the clinic. Fifty percent of the women did not do any sort of fertility treatment following diagnosis. Pregnancy happened only in 24% women. Most (75%) of the pregnancy were spontaneous. Six women said they were divorced or had strained marital relationship. The persistence or recurrence of pain with or without sonographic diagnosis of cyst occurred in 38% women. **Conclusion:** Women with infertility and endometriosis have their priorities change with affordability of treatment and as well as severity and impact of symptoms.

Keywords: Endometriosis, Infertility, Reproductive, Quality of life.

INTRODUCTION

Endometriosis is a chronic, recurrent, inflammatory condition associated with the presence of functioning endometrial tissue outside uterus. Endometriosis affects around 10% of women in reproductive age. The women with endometriosis may be asymptomatic with an incidental finding of chocolate cyst or ovarian endometrioma at sonogram. They may present with pelvic pain such as dysmenorrhoea, dyspareunia, intermenstrual pain, dyschezia or with menstrual problems such as heavy menstrual bleeding or irregular menstrual bleeding.^[1] Infertility occurs in around 47-50% of women with endometriosis. The probable mechanisms by which endometriosis cause infertility include inflammatory or immuno-modulatory changes within pelvis, disturbed tubo-ovarian relationships resulting in ovulatory, tubal and uterine-endometrial dysfunction. Endometriosis can broadly be described as peritoneal endometriosis, ovarian endometriosis and deep infiltrative endometriosis (DIE). DIE is diagnosed when the depth of endometriosis lesions are $> 5\text{mm}$ in the rectovaginal septum. The surgery may not be able to remove all the endometriosis lesions and restore the anatomy completely.^[2] Endometriosis has high recurrence rate following surgical treatment, around 20% after 2 years and 50% after 5 years.^[3] Non-steroidal anti-inflammatory agents combined with hormonal suppression of the endometriosis lesions for variable periods comprise the medical management of endometriosis.

Infertility is defined as failure to conceive within one year of conjugal life. In normal couples, fecundity or the chance of getting pregnant is 0.15 to 0.20 per month and it declines with age. Women with endometriosis tend to have lower monthly fecundity of about 0.02 to 0.1 per month.^[2] Pregnancy with endometriosis is associated with lower live birth rate due to various obstetric complications.^[4] When an infertile woman is diagnosed to have endometriosis, the pain and menstrual abnormalities and relatively poor prognosis associated with the advanced form of the disease add to the physical, emotional and financial burden of infertility itself. There are many qualitative studies exploring the anger, anxiety and depression associated with the persistent and recurrent pain, uncertainty of prognosis associated with endometriosis. The severity of pelvic pain can be amplified by anxiety and depression.^[5] Women are worried and depressed about infertility and fertility problems strain long term relationships.^[7] The physical and mental health status and the quality of life are adversely affected by the pelvic pain and infertility.^[8] Psychological interventions may complement the medication to achieve adequate symptom relief.^[9] The significant social and psychological impact of this chronic and often debilitating disease must be taken into consideration for comprehensive management of the women with endometriosis and infertility.^[10] Infertility is a quite unfortunate situation for the women in Bangladesh. Early marriage is prevalent in this developing country

with predominant Muslim population. Fertility is strongly identified with the role of women in family and society. Most of the women attending the public health care sector are of low education and economic status.^[11] The objectives were to analyze what infertility treatments they pursue, pregnancy happened or not, whether there is persistence or recurrence of pain and cyst and what strategies they have for coping with it.

MATERIALS AND METHODS

This was a qualitative study of the infertile women who were counseled in the Endometriosis Clinic, a dedicated center of the Infertility unit of the Department of Obstetrics and Gynecology of Bangabandhu Sheikh Mujib Medical University. The women received consultation in Endometriosis Clinic over a period of 5 years from 2014 to 2018. Their details including contact number were recorded. Following consultation, brochures were provided for education about the chronic nature and risk of recurrence of the disease. The records of the Endometriosis clinic were used for data about their symptoms at first visit, type of surgery and the stage of endometriosis at the time of surgical diagnosis. The women were contacted over cell phone in the month of July 2020. When the author SI called the cellphone numbers, many were out of service or did not respond. Quite a number of women provided the number of their husbands or relatives. The numbers of the women were then collected from them, so that SI could

directly talk to the women. Short semi-structured interviews were taken with both open and close ended questions. The answers were transcribed simultaneously or immediately thereafter. Data collected from the records of Endometriosis Clinic and from the semi-structured interview were used for qualitative analysis. Qualitative analysis was done about the fertility treatment they had after surgical or sonographic diagnosis of endometriosis. The occurrence of pregnancy, the fertility treatment leading to pregnancy, the persistence or recurrence of pain and cyst and the coping strategies were analyzed in the context of existing literature and evidence based medicine.

RESULTS

The average age at the time of first visit to Endometriosis Clinic was 27.56 years (20–37 years). The follow-up interview was after an average of 4.24 years (2-6 years). The women are now of average 31.84 years (range 22-43 years). Most of the women are residing in Dhaka city, followed by those from remote (more than 2 hours journey from Dhaka) districts of Bangladesh like Panchagar, Nilphamari, Netrokona, Bhola, Barguna etc. [Table 1]. Two women were lost to follow up after they were advised laparoscopy, following sonographic diagnosis. Twelve (n=12, 24%) women were advised in vitro fertilization (IVF) because they had advanced endometriosis with bilateral tubal block or grossly distorted tubo-ovarian relationship. Twenty-nine (n=29, 58%) women were advised intrauterine

insemination (IUI) because tubes were patent with normal tubo-ovarian relationship or because they had advanced endometriosis but could not afford IVF. Ovulation stimulation (OS) with oral drugs only was offered to 4(8%) women. They had minimal or mild endometriosis at laparoscopy, or did not do laparoscopy or did not afford or agree to IUI. Ovulation stimulation with oral drugs or injectable gonadotropins was done by 9 (18%) women, either in our center or in other center or with local gynecologists. Ovarian stimulation with gonadotropins followed by Intrauterine insemination was done by 18 (36%) women. Some women, from Dhaka or remote areas have done IUI only once in 2-4 years following laparoscopy. The cost of gonadotropins and IUI, or the distance they have to travel are the barriers. In Vito Fertilization with or without antecedent IUI or OS was done by only 6 (12%) women. Most of the women do not have a plan to do IVF. Pregnancy happened only in 12 out of 50 (24%) women. Most of the pregnancy (9/12, 75%) were spontaneous. The spontaneous pregnancies occurred from 4 months to two years after laparoscopy. Pregnancy followed IVF in 2 woman (2 out of 6 IVF, 33%) and OS in one women (1 out of 9 OS, 11%). Four women (4 out of 6 IVF, 66%) had IVF failure. Two of them were advised IVF with donor oocytes. One of them will not go for IVF with donor. One woman cannot afford a second time IVF after the first one failed [Table 2-4]. There was no persistence or recurrence of pain, cyst or heavy

menstrual bleeding in 20 (40%) women. The persistence or recurrence of pain with or without sonographic diagnosis of cyst occurred in 19 (38%) women. Six women struggle with heavy menstrual bleeding. They cope with the problems by taking NSAID's and hormonal suppression, intermittent or continuous for variable periods. Two women say they are free from pain for around one year after taking an alternative medicine (a combination of herbal medicine imported from India) we prescribed for six months. One woman, when she was 27 years old, presented with dysmenorrhea, dyspareunia, chronic pelvic pain and bowel symptoms. She had umbilical endometriosis and sonography revealed a large chocolate cyst and moderate ascites. Laparoscopy confirmed hemorrhagic ascites with bilateral chocolate cyst. Cystectomy was done on one side and fenestration of a small chocolate cyst was done on the other side. She was adequately counseled about the need for IVF and the risk of recurrence. A few months later she presented with recurrent chocolate cyst. We did suppression with continuous letrozole and norethisterone for 6 month and then hysterosalpingography which revealed unilateral patent tube. Intrauterine insemination was done, but failed. Two years later again she developed chocolate cyst for which she was treated with danazol for 8 months. For last 3 months she has a painful mass at the site of drain placement. A 30-year-old woman, and a mother of one living child had laparoscopy and diagnosis of stage IV endometriosis. She could not

come back to us from Jessore for IUI or the treatment of the persistent pain as her husband was always away for his service. She had hysterectomy to become pain free when she was 32 years old [Table 5].

Table 1: Demographic characteristics

Parameters	N (%)
Age at first visit 27.56 (20-37) years	50 (100%)
Age at follow up interview 31.84 (22-43) years	50 (100%)
Residence	
Dhaka city	25 (50%)
Nearby districts	9 (18%)
Remote districts	16 (32%)
Associated uterine factor	
Adenomyosis	3 (6%)
Fibroid	4 (8%)
Surgery	
Once	37 (74%)
Twice	6 (12%)
Twice	3 (6%)
No surgery	4 (8%)

Table 2: Presenting symptoms

Symptoms	N (%)
Infertility	49 (98%)
Dysmenorrhoea	45 (90%)
Dyspareunia	18 (36%)
Chronic pelvic pain	21 (42%)
Heavy menstrual bleeding	15 (30%)
Acyclic bleeding	10 (20%)
Bowel symptoms	19 (38%)
Painful Umbilical nodule	2 (4%)

Table 3: Type of Surgery

Type of Surgery	N (%)
Only Laparoscopy	36 (72%)
Only Laparotomy	2 (4%)
Laparoscopy preceded or followed by laparotomy	7 (14%)

Table 4: Stage of Endometriosis

Stage of Endometriosis	N (%)
Stage I	1 (2%)
Stage II	1 (2%)
Stage III	6 (12%)
Stage IV	38 (78%)

Table 5: The prevalence of persistent or recurrent symptoms and their coping strategies in the infertile women with endometriosis.

Parameters	N (%)
Persistent or recurrent symptoms	
Cyst	5 (10%)
Pain	14 (28%)
Cyst and pain	5 (10%)
Heavy menstrual bleeding	6 (12%)
Coping strategies with medication	
NSAIDs	9 (18%)
Hormonal suppression ± NSAIDs	25 (50%)
Repeat Surgery	
Conservative surgery	3 (6%)
Hysterectomy	1 (2%)

DISCUSSION

This was a qualitative analysis of fifty women with endometriosis desiring pregnancy who were seen in the dedicated Endometriosis Clinic of a Public Medical University of Bangladesh. The study reveals that most of the women cannot afford fertility treatment following diagnosis. The study included semi-structured interview over cellphone, so women from remote districts, quite a substantial number (n=16, 32%), could be included. Most of the women were young compared to previous qualitative studies,^[8-9,12] as in our situation, early marriage is prevalent

and the presenting symptom is infertility. The condition of infertility with the uncertainty of prognosis, expenses of treatment involved strain the relationship with husband and family, threatens breakdown or actually cause breakdown of families. The male partners of the women with endometriosis and infertility are affected in various ways regarding sex and intimacy, planning for children, working lives and household income leading to difficult emotional responses like helplessness, frustration, worry and anger.^[13] This is reflected in some husbands seeking or getting separation or divorce from their suffering wives. Not all women with endometriosis experience infertility. About 30-40% women with endometriosis find it difficult to get pregnant. The monthly fecundity is reduced to 2-10% in endometriosis compared to 15-20% in the fertile couples.^[14] Advanced endometriosis like stage III or stage IV have more severe adverse effect on infertility. Besides endometrioma and impaired tubo-ovarian function, factors like pelvic inflammation, impaired oocyte quality, and endometrial receptivity may be responsible. However as we have seen in this study the reproductive outcome may not be always predicted by the stage of the disease.^[15] Observational, non-randomized trials on the effect of surgery on endometriosis related infertility, partly independent of lesion types, reasonably suggest the enhancement of pregnancy rates to levels between 10 and 25%, lower to that suggested previously.^[16] Pregnancy occurred spontaneously in

18% of our women, a finding similar to that of the review. This is well inferior to the alleged 50% fertility in women with endometriosis. Controlled ovarian hyper-stimulation and IUI appears to have better outcome than no treatment in stage I and stage II endometriosis.^[17,18] But the chance of pregnancy is much lower in women who had surgical treatment of stage III and stage IV endometriosis. ESHRE recommends COS-IUI only in stage I and II endometriosis within 6 months following surgery.^[5] IVF is the most effective treatment of endometriosis related infertility.^[5] Reformation of adhesions is found in 37% to 72 % of operative sites and 51% of patients develop new adhesions after reproductive procedures by laparoscopy.^[19] Repeat surgery was done in 9 (18%) women. Repeat surgery is more likely associated with new disturbance in tubo-ovarian relationship or patency of the tubes, in addition to further damage to ovarian follicles. The pregnancy rate is diminished after repeat surgery to half of that after first surgery.^[15] Adenomyectomy with fertility preservation can be offered for infertile women with severe symptoms.^[20] The evidence is strong in favor of the effectiveness of combined OCP in minimizing recurrence of endometrioma following surgical removal.^[15,21] There is strong evidence that laparoscopic removal of endometriotic lesions is effective in reducing pain. Laparoscopy is preferable to laparotomy because lesions are better visualized with magnification and illumination and

removed with precision, with less risk of postoperative adhesion. Removal of deep endometriosis needs highly specialized surgery, available only within centers of expertise. Cystectomy, where possible is preferable to drainage and coagulation to minimize recurrence of pain and cyst and to enhance fertility.^[15] Evidence exists showing that laparoscopic ablation or excision of endometriosis in stage I and II improves fertility.^[17] There has been no assessment by randomized controlled trials (RCT) of the efficacy of surgery in improving fertility in stage III and stage IV and in deep infiltrative endometriosis. The chance of natural conception postoperatively is likely to be determined by the functional appearance of fallopian tubes at the end of laparoscopic procedure.^[22] IVF improves pregnancy rate above expectant management, still the success is lower than IVF in other conditions. Post-operative medical adjunct therapy neutralize the chance of pregnancy at a time when fertility has been improved by surgery.^[15]

Limitations of the study

Small sample size and short time of period was limitation of the study. So, the result of the study may not reflect the exact picture of the whole country.

CONCLUSION

Endometriosis is a chronic and recurring disease with profound effect on the life of women who suffer. There is relentless effect on fertility, a crucial aspect of women's life. Women with endometriosis most of the time deserve

long term individualized care. Priorities change with affordability of treatment and fertility wish as well as severity and impact of symptoms. Patients' satisfaction needs improvement by providing the most appropriate fertility treatment according to their preference and ability, allowing for frequent follow up and adequate counselling with empathy. Surgery should be combined with IVF to increase fecundity of infertile women with stage III and stage IV endometriosis. Surgery should be laparoscopic cystectomy and adhesiolysis with an expert team.

REFERENCES

1. Agarwal SA, Chapron C, Goudice L, Laufer MR, Leyland N, Missmer SA et al. Clinical diagnosis of endometriosis: a call to action. *Am J ObsGyne* 2019; 220(4): 354-364
2. Vitali SG, La Rossa VL, Rapisarda AMC, Lagana AS. Endometriosis and Infertility: the impact on quality of life and mental health. *J Endometr Pelvic Pain Disord* 2017; 9(2):112-115 DOI: 10.5301/je.500274
3. Guo SW. Recurrence of endometriosis and its control. *Hum Reprod Update* 2009; 15(4):441-461 doi 10.1093/humupd/dmp007
4. Rowe H, Quinlivan J. Let's not forget endometriosis and infertility amid covid-19 crisis. *J PsychosomObstet&Gynaecol* 2020; 41(2):83-85 DOI:1080/0167482X.2020.1757200
5. Khine YM, Taniguchi F, Harada T. Clinical management of endometriosis associated infertility. *Reprod Med Biol* 2016;15: 217-225
6. Lagana AS, La Rosa VL, Rapisarda AMC, Valenti G, Sapia F, Chiofalo B. Anxiety and depression in patients with endometriosis: impact and management challenges: *Int J Women's Health* 2017;9:323-320
7. Young K, Fischer J, Kirkman M. Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *J Fam PlannReprod Health Care* 2015;41:225-234

8. Fourquet J, Baez L, Figueroa M, Iriarte I, Flores I. Quantification of the impact of endometriosis symptoms on the health related quality of life and work productivity. *FertilSteril* 2011; 96:107-12

9. Faccin F, Barbara G, Saita E, Masconi P, Roberto A, Fedele L et al. Impact of endometriosis on the quality of life and mental health: pelvic pain makes the difference; *J PsychosomObstetGynecol* 2015; 36(4):135-141 DOI: 0.3109/0167482X.2015.1074173

10. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013; 19(4): 428-439

11. Ishrat S, Deeba F, Fatima P. Sociodemographic profile of infertile women presenting at Bangabandhu Sheikh Mujib Medical University. *J Shaheed Suhrawardy Med Coll* 2015; 7(2): 63-65

12. Moradi M, Parker M, Sneddon A, Lopez V, Eliwood D. Impact of endometriosis on women's lives: a qualitative study. *BMC Women's Health* 2014; 14:123 <http://www.biomedcentral.com/1472-6874/14/123>

13. Culley L, Law C, Hudson N, Mitchell H, Denny E, Raine-Fenning N. A qualitative study of the impact of endometriosis on male partners. *Hum Reprod* 2017; 32(8): 1667-1673

14. Young K, Fisher J, Kirkman M. Endometriosis and fertility: women's accounts of healthcare. *Hum Reprod* 2016; 31(3):554-562 doi: 10.1093/humrep/dev337

15. Johnson NP, Hummelshoj L. Consensus on current management of endometriosis. *Hum Reprod* 2013; 28(6):1552-1568

16. Vercellini P, Somigliana E, Vigano P, Abiati A, Barbara G, Crosignani PG. Surgery for endometriosis associated infertility: a pragmatic approach. *Hum Reprod* 2009; 24(2):254-269

17. Brown JA, Farquhar C. Endometriosis: An overview of Cochrane Reviews 2014. Article in Cochrane database of systemic reviews (Online) DOI:10.1002/14651858.CD009590.pub2.source Pubmed

18. Danillidis A, Pados G: Comments on the ESHRE recommendations for the treatment of minimal endometriosis in infertile women. *Reproductive Biomedicine Online* 2017; Article in Press <http://doi.org/10.1016/j.rbmo2017.10.103>

19. Trimbos-Kemper TCM, Trimbos JB, van Hall EV. Adhesion formation after tubal surgery: results of 8 day laparoscopy in 188 patients. *FertilSteril* 1985;43:395-400

20. Osada H. Uterine adenomyosis and adenomyoma : the surgical approach. *FertilSteril* 2018;109 (3): 0015-0282 <https://doi.org/10.1016/fertnstert.2018.01.032>

21. Denny E, Weckesser A, Jones G, Bibla S, Daniels J, Bhattacharya S et al. Women's experiences of medical treatment for endometriosis and its impact on PRE-EMPT trial participation: a qualitative study. Pilot and feasibility studies 2018;4:168 <https://doi.org/10.1186/s40814-018-01358-5>

22. Cook AS, Adamson GD. The role of Endometriosis Fertility Index (EFI) and Endometriosis scoring systems in predicting infertility outcomes. *CurrObstetGynecol Rep* 2018; 2:186-194 DOI 10.1007/s13669-013-0051-x

Source of Support: Nil, Conflict of Interest: None declared